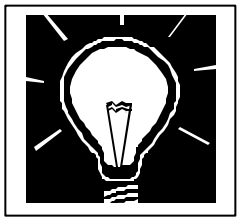

Connecting Minds – Dementia Care Newsletter

Wisconsin Bureau of Aging and Long Term Care Resources
Cathy Kehoe, Alzheimer's Service Developer

*The Wisconsin Bureau of Aging and Long Term Care Resources received in July 2000 an **Alzheimer's Demonstration Grant** from the **Federal Administration on Aging** to improve quality of, and access to, long term care services for people with Alzheimer's disease and related dementia across the state. As part of the grant, **Cathy Kehoe, Alzheimer's Service Developer,** issues this quarterly newsletter for people who work in the long term support system.*

Food for Thought: Care Planning for People with Alzheimer's Disease

A collection of questions posed by care managers over the last three months.

When Someone You Care for is Declining:

Q: We have a client who has been attending a Senior Center for a long period of time without any major problems besides some gradual declining memory. Recently, however, he is very confused and has shown marked signs of a decline in function. He lives alone and his family lives an hour away. How do we help him?

Sudden marked decline can be an indication of an illness or infection, problem with medications, dehydration or a nutritional problem. It's always important to assess rapid declines right away, as they can usually be helped. Making the family aware of the problem and its history should be done immediately. A trip to the gentleman's doctor should be made quickly to address any immediate health concerns. Connecting the family with a good dementia diagnostician is also necessary. A full diagnostic work-up can help with long-term decline. There are several medications currently on the market that slow the progression of Alzheimer's disease and allow a person to be independent for longer periods of time. Generally, the earlier in the progression of the illness, the more successful the medication. In addition, diagnostic clinics help families plan for long-term issues such as guardianship and relocation, they evaluate medications, provide counseling and connect families with resources.

There are several **dementia diagnostic clinics** around the state that specialize in dementia treatment. In addition, many private physicians are good at working with dementia patients. The list of clinics can be found on the Wisconsin Alzheimer's Institute web site: www.medsch.wisc.edu/wai. **Private physicians can be identified by your local Alzheimer's Association Chapter** www.alz.org .

Families are usually willing to take action, but are often unsure of what to do and frightened about the future possibilities. **Connecting the family with the local chapter of the Alzheimer's Association will give the family the support and education they need**

to make informed choices. There families can take advantage of consultation and educational services to assist them with long-term planning, which is so important when a person is in the earlier stages of decline - before a crisis hits and it's too late. There are also providers of services like companion care, adult day services, volunteer agencies, and visiting nurses or home health care that can help the person with dementia stay independent. In addition, residential options for people who need supervision but not a nursing home are available. The Alzheimer's Association often knows exactly who these people are and how to access their services.

Local County Aging Units and Resource Centers are another source of help for families. Their Information and Referral professionals will provide referral and support group resources, do home visits and evaluate financial needs. Benefit Specialists on staff can help with sorting out Medicare and other medical coverage issues, review sweepstakes and mail offers for fraud, help recover money, and review bills.

Coping with Sexual Issues and the Person with Dementia:

Q: We have a person living in a facility who is becoming "too friendly" with one of the other residents. The facility wants to work with us to prevent any inappropriate sexual behavior from occurring. What can we do?

This subject can be sensitive to anyone, even when dementia is not an issue. The complexities of this topic are just beginning to be discussed at the state level by a workgroup the Department of Health and Family Services has assembled to help address these complicated issues occurring in facilities. The responses here are reflective of situations where the person having dementia does not have a history of abusive or sexually aggressive behavior. Here are some general guidelines that can be followed to work through the situation and come up with potential solutions. As in any complex situation, it is imperative that you **document all information gathered, actions taken, strategies involved**, **responses and ongoing patterns over time.** Here are some first steps:

Assess the person for potential causes of behavior related to health & environment.
Protect any potential victims of the behavior from unwanted advances, and address their reactions if they have been victimized, regardless of the situation.
Establish a plan for, and conduct, close monitoring of the situation. Then you are ready for closer examination of the situation for further intervention.

Many misconceptions can color our responses, as providers, to sexual situations. There have been extreme cases where facilities have gone so far as to separate men from women in locked units. Such quick "fixes" only punish and isolate everyone in the facility, and don't address the issues**.** To identify solutions, it is helpful to understand things from the perspective of the disease, the person and the environment.

Potential Causes of Behavior:

1) **The Illness:** Alzheimer's disease, and other dementia involving damage to certain areas of the brain, can effect sex drive in the following ways:
   - **Decrease in inhibition:** which the person cannot perceive in her/his own behavior. This is due to damage to the part of the brain that controls reasoning and inhibition.
   - **Increases in actual sex drive** are related to hormonal imbalances that can be potentially treated if they result in severe problems for the person.
   - **Needs for safety and reassurance** related to the person's level of confusion. In an unfamiliar environment all of us have an instinctual need to be comforted, and the more confusion, the greater the need for reassurance. When a person with dementia loses his/her reasoning skills, this need becomes paramount.
2) **The Person:** To examine causes for behavior, **we need to ask about who this person is.** The person's **past associations, routines, habits, and relationships** will have a great deal of bearing on the current situation because it's the only "reality" that person can

remember now. Was he someone who was married to a loving wife who he held every night for fifty years? Did she have a pattern of equating sexual contact with men as her only form of intimacy and closeness? Was he someone who took particular pride in his attractiveness to women as a form of acceptance? What are the person's needs for privacy and intimacy?

3) **The Environment:** Here are things to examine which could be behavioral influences:
   - **"Whose problem is this?"** Is the situation creating a problem for staff, for other clients, for family, or is the person experiencing a problem?
   - **What is the context?** Does the person seem to always "target" the same person? Is there a consistent message addressing the behavior coming from all people involved in the person's care?
   - **What is going on around the person at the time of the incident?** What conditions (noise, arguing, bedtime, bath time, in a public area) are around the person at the time of the behavior? Who is the person with, what are they doing? Environmental associations can be strong triggers to someone's past, and must be considered.

Intervention Strategies:

When considering anyone's care who has dementia, there are hallmarks that must guide us.

- **Retaining the person's dignity**
- **Entering the person's world to understand her/him and the situation**
- **Honoring the person's reality**
- **Providing the person with help not harm**

Learn about things that were positive influences and experiences for this person. *The key to addressing behavior issues in a person with dementia is supporting them to re-connect with positive things from their past, and helping them to sort these out as positive connections.*

- **What is the person saying?** It may be helpful to sit and talk with the person and help them to **name what they are feeling.** All behavior is communication. It may be the only way the person is able to communicate feeling and needs. Help her to identify opportunities to meet her needs through other activities that she enjoys, addressing other intimacy needs such as social and emotional intimacy.
- **What is actually happening sexually?**

- Cuddling, holding, touching another is usually a need for closeness that the person may have had throughout her life. Creating opportunities for closeness and touch that are non-sexual may help (hand massages, games where people hold hands, sleeping with a body pillow, hugs from staff, pats on the back, visits from pets and children, etc.)
- Evidence of a "hypersexual" state – frequent masturbating, preoccupied with sexual activity. This indicates the need for medical intervention. There are medications which can be very helpful (see following article interviewing a psychiatrist). Assuring and respecting privacy, along with a consistent plan for addressing the situation if it occurs in public places, is also needed.
- Exposing himself to others: If previous exhibitionistic behavior is ruled out, he could be seeking help for discomfort (UTI infection) or reminding himself that he's headed for the bathroom. These are both common. Using visual cues like pictures identifying routes to the bathroom can provide different reminders for the person to use.

- **Minimize Environmental Factors:** Gather all staff to discuss contributing issues, develop strategies, and implement a plan where everyone is giving the same consistent responses, message and supervision. Many strategies should be identified with the ability to try different things. Case managers, guardians or family, staff and the clients involved should be informed of and have input into the plan.

Resources:

Carly Helen OTR/L: **"Alzheimer's Disease – Activity Focused Care"** available through Butterworth Heinemann www.bh.com 719-904-2500.

Jane Verity **"Dealing Constructively with Client's Sexual Behavior"** www.DementiaCareAustralia.com (03)9727-2744.

Edna Ballard A.C.S.W. & Cornelia M. Poer, B.A.**"Sexuality and the Alzheimer's Patient"** Available through Duke Family Support Program 919-684-2328.
" A Thousand Tomorrows" Video on Alzheimer's disease and intimacy in couples.
"The Tie That Binds-An Exploration in Sexual Intimacy of Alzheimer's Couples" Both available through Terra Nova Films www.terranova.org 800-779-8491.

Interview With A Medication Specialist

Thanks to the Waukesha County Department of Senior Services, who responded to the last newsletter, sighting "freedom from psychotropic medications" as an outdated concept for people with dementia based on new drugs and techniques available.

Interview: Dr. Cary Kohlenberg, Chairman Department of Psychiatry, Medical Director Inpatient Geriatric Services, Waukesha Memorial Hospital.

Discussion: What is your Approach to the Use of Psychotropic Medications in People with Dementia?

New Medications: The use of medications in people with dementia has changed significantly during the last ten years, with the advent of new drugs. Previous psychotropic medications used were primarily the old anti-psychotic drugs (like Haldol), which have major side effects and are highly sedating. Now there are not only new anti-psychotic drugs, but also new classes of drugs, which are more specific to dementia and other problems, with few side effects. The image people have of dementia patients being drugged and incoherent is the product of inappropriate use of these old anti-psychotic drugs. New regulations in force are helping to eliminate the use of these drugs in hospitals and nursing homes. The new drugs include **cognitive enhancing drugs** (Aricept, Reminyl, Exelon), drugs for treating **depression and anxiety**, new psychotropic medications (like Seroquel or Zyprexa), and **other types of drugs** (such as blood pressure medication) that can be used in a psychotropic manner (e.g., for calming effects). Use of these medications can allow people with dementia to remain in the community and have a better quality of life.

Approach to Treatment: My bottom line in assessing a patient is to examine medical causes first for his/her problem**. The three biggest causes of behavioral issues in people with dementia are untreated or under treated pain, urinary tract infections and constipation.** These are commonly overlooked because the person has lost the ability to communicate these problems to others. I also look for drug interactions between medications the patient is taking. Stomach upset and constipation can be side effects. Some medications can cancel each other out. For example, the anti-depression medication Paxil has the opposite effect on the brain as the cognitive enhancer Aricept. In addition, Paxil should be avoided in elderly patients, especially people with dementia, because it is very sedating, effects blood pressure, and has many side effects.

I always evaluate the person immediately to see if they can benefit from the use of cognitive enhancing medications**. Studies show that drugs like Aricept have the biggest impact when given early in the illness.** Research indicates that early use

of these medications can cause the person to regain as much as 1 year of lost function, and decrease the normal progression of the disease over time. The biggest mistake that family doctors make when putting a patient on these drugs is discontinuing the medication after only a few months because no progress is seen. In later stages of the illness no change is good – it means the progression has been slowed. Sometimes it takes a year to see the full benefit of the drug. **The second areas I examine for behavioral triggers are environmental causes and improper caregiving approaches**. After I rule these things out, I consider the use of medications to influence behavior.

My philosophy is to start with the most benign (mild) treatment available, which targets and stabilizes the specific symptoms in the person. Here are some examples.

Sexual Behavior Problems – usually there are two types, non-aggressive (which is related to normal sexual feelings complicated by confusion) and aggressive (which means acting out and initiating sexual contact.) For the non-aggressive, I refrain from medication. For the aggressive, I try these three strategies beginning with the least restrictive. (This is usually seen in men, very few women).

- Begin with an anti-depressant that has sexual side effects, to reduce sex drive and sexual function.
- If aggressive behavior continues, try estrogens to reduce sex drive.
- Continued sexually aggressive behavior of a severe nature would indicate use of a mood stabilizer (like Depakote) or a new anti-psychotic medication (like Seroquel or Zyprexa) which has few side effects compared to the older anti-psychotic drugs. Over time this medication would be decreased in increments to see if it is still needed.

*In any behavioral situation involving aggression I follow these same steps, first trying an anti-depressant or other more benign drug, then progressing to a mood stabilizer or a new anti-psychotic medication if behavioral severity persists. The new medication Zyprexa comes in a wafer form that dissolves on the tongue, making it possible to avoid giving shots – which only further agitate someone with dementia.

Apathy Syndrome – is where someone is very flat emotionally, and it is common in people with Alzheimer's disease. I begin with a cognitive enhancer like Aricept. In someone with Alzheimer's disease, the apathy may lift. If the problem is actually depression, there will be no change in the apathy. Then I would go to a very mild, low side effect anti-depressant. Sometimes the depression and dementia occur together and are treated together using anti-depressants other than Paxil.

Earliest Alzheimer's Warning Signs. We have found, in patients who are diagnosed with Alzheimer's disease, that 2-3 years before the diagnosis they experience a period of mild social withdrawal and social isolation. I encourage people who notice this in their loved ones to have them evaluated for early cognitive decline. Remember that the earlier a person is diagnosed, the better these new medications will work to help stave off the illness.

Dr. Kohlenberg is a practicing psychiatrist and educator. He presents seminars on medications and older adults. For more information please call his office at **262-513-0700.**

What's On the Web: Medication Information and Prescription Drug Discounts

Prescription Drug Treatments and Alzheimer's Disease:

The Web MD web site has many helpful articles on Alzheimer's disease and the use of interventions including medications, plus specific drug information: http://my.webmd.com/content/article/1626.50806

Aricept Lowers Alzheimer's Health Care Costs – A Study: http://www.bioportfolio.com/news/btech_031902_1.htm

Article comparing anti-psychotic drugs, written for health care professionals. It is quite comprehensive. You can read it, fill out a form and pay $15.00 to get continuing education credits if healthcare professional! Full article is at www.mhsource.com.

Prescription Drug Discount Cards for Medicare Recipients:

Pfizer Share Card: seniors pay $15 for a 30-day supply of Pfizer medicines. (Including Alzheimer's medication) For Pfizer Share Card information visit pfizer.com **or call 1-800-717-6005.**

The Novartis Care Card provides a 25% discount off the wholesale list price of drugs that Novartis manufactures.(including those for Alzheimer's). For Novartis Care Card information **call 1-866-974-CARE (2273)** or visit pharma.us.novartis.com or www.pswi.org/professional/cards/carecard.htm

Eli Lilly Senior Discount Card: allows low-income seniors to pay a flat fee of $12 for a 30-day supply of any Lilly retail drug. **For information, call (877) RX-LILLY or visit** www.lillyanswers.com

GlaxoSmithKline Orange Card: provides prescription discounts of between 30% and 40%. **Call 1-888-ORANGE6** or visit http://www.gsk.com/press_archive/press_10032001.htm

Pharmacy One Card: Combines all discount programs onto one card. Call the National Association of Drug Store Chains at 703-549-3001 or visit www.nacds.org

Center for Medicare & Medicaid Services can help with info; **1-800- MEDICARE** or visit http://www.medicare.gov/Prescription/Home.asp

Contributions to This Newsletter are Welcome! Please contact:

Cathy Kehoe, Alzheimer's Service Developer WI Bureau of Aging & Long Term Care Resources, PO Box 7851, Madison WI 53707
Office: 608-267-2439 Fax: 608-2673203 kehoecb@dhfs.state.wi.us

Sponsored in part by the Wisconsin Department of Health & Family Services.
This project was supported, in part, by a grant, number 02-90AZ236901, from the Administration on Aging, Department of Health and Human Services, Washington D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.